

Community Plan for Epileptics

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THE PROBLEMS in rehabilitation of persons with epilepsy differ in many respects from those encountered in dealing with physical handicaps of other types. For one thing, there is lack of unanimity within the medical profession concerning definition and diagnosis of the condition. For another, the public is considerably confused by much misinformation and little correct information. Despite present-day knowledge about epilepsy and the availability of good medical treatment, many people still think of the affliction as a "taint" and believe it to be associated with insanity.

Epilepsy, a condition in which there are recurrent episodes of disturbance in consciousness, varies in form and severity. Some spells are only momentary lapses, while others are severe generalized convulsions. The spells may be simple automatic movements or peculiar actions associated with unresponsiveness and a complete lack of memory. The seizures are manifestations of a brief disturbance in functioning of the brain, which very often is the result of an old, forgotten or unknown injury. One of the peculiarities of the handicap produced by epilepsy is that the person may be entirely normal in appearance, manner, and intellectual ability between seizures. The suddenness with which the attack comes and helplessness felt by those nearby add to the mystery of the condition.

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School authorities, employers, and fellow workers generally do not like to have an epileptic around. Children with epilepsy are commonly sent home from school after an attack, and frequently they are excluded from regular public school classes altogether. Ostracism and family feelings of shame, which may be present, make a bad situation worse. The young person who has a seizure while at work may lose the job, and a long hard road of having to lie about his condition is begun if any work at all is to be had. Capacity to work is not the measure. The adult who has supported his family finds after developing epilepsy that life can be very grim. Discrimination and enforced dependence lead to lack of confidence and often to increased difficulty in controlling the seizures.

Because of the large number of persons with epilepsy—it is estimated that there are now about one and one-half million in the United States—the Veterans Administration in 1949 appointed a medical committee to survey the problem among veterans in the Los Angeles area. This survey revealed that 75 percent of the veterans with epilepsy living in the community were unemployed and that a large percentage of this group were also under poor medical control. A number of veterans with epilepsy were in the hospital, and experience has shown that once in the hospital, epileptic patients tend to remain under the care of the Veterans Administration indefinitely.

In 1950 the Veterans Administration began a pilot study in employment of domiciled epileptic veterans. This study, in the form of an experimental workshop, was designed to determine the beneficial effects of steady, gainful employment on control of seizures, and to pro-

mote economic rehabilitation of the epileptic. In both these aspects the results have been more than encouraging. The shop operates through contracts with outside firms . . . operations simulate prevailing shop practices in private industry . . . employment is voluntary and placement is eagerly desired. The program has received the commendation of many who believe it to be modeled after the best medical and industrial traditions.

The success of this endeavor not only assured its continuation but also served as a stimulus for establishing a comparable workshop in the community for all persons, veterans and non-veterans, unemployed because of epilepsy. This shop, which began operation on January 16, 1956, is called Epi-Hab L.A. Inc. It is dedicated to the reintegration of the epileptic through medical control, industrial training, employment, and placement and is supported by grant funds from the Office of Vocational Rehabilitation, Department of Health, Education, and Welfare, matching private funds, and a variety of gratuitous services from the community. These services are in the fields of law, advertising, public relations, accounting, medicine, labor, industry, and engineering.

Drawing upon experience in the Veterans Administration workshop and, particularly, in the Epi-Hab project, we shall review specific aspects of the epilepsy problem in an industrial setting.

The Reject Syndrome

Not infrequently the individual with epilepsy denies his affliction and substitutes an entity which he describes as a dizzy spell, a blackout, a weak spell, or simply a peculiar feeling. He cannot accept epilepsy as a part of his life; the stigma is much too damaging to his self-esteem. Now and then he appears suspicious and reluctant to talk about his seizures. He is usually sensitive, defensive, and resentful, and sees himself as miscast in a competitive society.

The age of onset of the seizures is a most important factor in the development of this reject syndrome. Onset during infancy or early childhood, with continuation of the attacks for a number of years, tends to contribute significantly to the molding of the syndrome. Here

one is dealing with incorporated parental fear, guilt, resentment, and concern, and the distorted attitudes of the community, which tend to structure and foster the reject syndrome. Occurrence during adolescence may interfere with growth toward independence, feelings of security, and ability to establish warm interpersonal relationships, but the damage is usually less severe than at younger ages. The effect of onset of epilepsy on the already well-formed behavior patterns of the adult may be slight.

A census study of some 100 epileptics residing in the domiciliary unit of the Veterans Administration Center in Los Angeles found that approximately 64 percent of the group had not gone beyond grade school, 31 percent had never married, 49 percent of those who had married were divorced or separated, 89 percent had an unstable work history after onset of epilepsy, 5 years was the average length of hospitalization (with a range of 1 month to 24 years), and 84 percent of the group suffered from moderate to severe psychological incapacity. The instability factors in work, marriage, and emotional adjustment presuppose absence of motivation, presence of maximum dependency strivings, and desire for custodial care. Isolationism and social withdrawal signified by unwillingness to communicate with fellow patients, feelings of resentment, lack of appreciation, diminution of confidence, and a host of other maladaptive personality traits reinforced by lack of interest and drive were the telltale characteristics of this community.

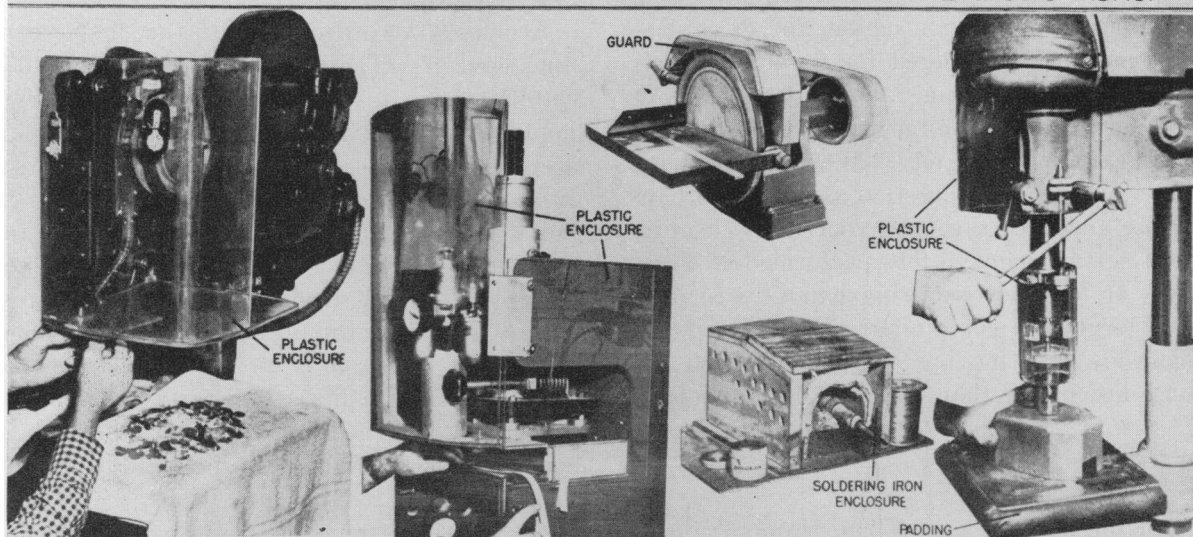
Let us see what happened when these human rejects were placed in circumstances in which their activity was rewarded, that is, in gainful employment. In this situation some of their maladjustive tendencies should be counteracted through a demonstration of usefulness by means of forced interdependence in work assignments and through a demonstration that in their community others are envious of their status, especially those domiciled for disabilities other than epilepsy.

The realignment of behavior patterns and the changes in attitudes required considerable time, patience, and effort. The crucial test of altered sentiments came when a number of these people were forced into the position where they had to choose between (a) continu-

can POWER MACHINES
be made safe for use by the
epileptic worker ?

Yes

THESE ARE SAMPLES OF SAFEGUARDS FIRST INTRODUCED INTO THE V.A. WORKSHOP



SOME SAFETY DEVICES HAVE BEEN REMOVED AFTER YEARS OF TESTING HAVE SHOWN THEM TO BE UNNECESSARY

Poster in an exhibit shown at professional meetings in 1955 and 1956.

ing their work and relinquishing their pension, the only form of security many of them had; and (b) giving up their work and continuing on their total non-service-connected pension.

Treatment of the rejection-and-dependency syndrome in the Veterans Administration industrial setting resulted in relinquishment of pension, the passive form of security, by 18 epileptic veterans. This voluntary surrender of the pension proves again that there are ways of motivating people, even those who belong to the hard core of unemployables, if status and self-esteem are substituted for dependency and rejection.

Limits of Job Placement

In assigning an epileptic to a job on machinery, consideration should always be given

to the dangers of the machine and to the nature of his seizures. If seizures are nocturnal or if there are distinct warnings prior to a seizure, there is no need to be greatly concerned. If seizures are of the grand mal or psychomotor type, the most important factors, according to the experience at Epi-Hab, are the level of intelligence and the degree of emotional stability of the individual.

In the beginning of the Veterans Administration project, extraordinary precautions were taken for the safety of the employees. Projecting portions of machines were covered with foam rubber and other soft padding to prevent injury in the event of seizures. Transparent plastic was used freely to cover moving parts of the machines so that they would remain in full view. However, experience has shown that the unusual safeguards are no more effective

tive against injury than the standard measures used by industry, and many of the experimental devices have therefore been removed.

Should the person with epilepsy work with machine tools which are ordinarily considered dangerous by industry, but which would raise his level of skills and thereby increase his potential for independence? Yes, of course, he can use most of them. A few—the lathe, the heavy hydraulic press, the heavy stamping machine, the milling machine, for example—have not been considered for use at Epi-Hab. Conservative thinking is still in order, for there are definite limitations to what the epileptic can do with safety. Where to draw the line, however, is a question that can perhaps best be answered through experience. Limitations pertain more to jobs performed at elevations or to those requiring exposure to open pits, large vats containing solvents, explosive materials, and moving equipment which can cause loss of life than to other types of jobs.

Seizures and Accidents

During the first year of Epi-Hab operations, 134 applicants were psychologically and socially screened for employment, and 57 were hired, 53 men and 4 women. Of the 57 hired, 16 were released for one of the following reasons: (*a*) left the State, (*b*) obtained a job closer home, (*c*) was absent excessively, (*d*) was uncooperative, (*e*) had serious personality problems. The capacity of the Epi-Hab plant is 50 employees. At the end of the first year, 41 employees were holding a variety of machine, subassembly, and electronic jobs, and 9 jobs were yet to be developed and filled.

The total number of man-hours worked at Epi-Hab was 42,221. During these hours there were 205 seizures; 194 were the grand mal type, the most disturbing kind in the employment situation, and 11 were of the Jacksonian or psychomotor variety. Time lost from work because of seizures amounted to 126 hours and 41 minutes, an average of 32 minutes, at a cost of 74 cents, for each seizure. Twenty-three of the 57 employees hired, or about 40 percent, experienced seizures while in the shop. Interestingly, 10 percent of the employees had

70 percent of the seizures, and one individual had 45 percent of the seizures. The employees having most of the seizures had the majority of their attacks during the first few weeks of their employment, a finding that supports the idea of progressive decrease in seizure frequency and intensity with passage of time and acquisition of confidence in the job. The policy of the shop is to return a man to his job soon after his seizure.

Accidents recorded during the first year numbered 27. These occurred to 18 of the 57 employees, or to 31 percent of the working population. The distribution of the accidents according to type and severity is as follows: 20 accidents not due to seizures in which first aid was given and the individual returned to work immediately; 1 accident not due to seizures in which medical treatment was required for severe thumb laceration, with some time being lost from work; 4 accidents due to seizures in which first aid was given and the individual returned to work immediately; 2 accidents due to seizures in which medical treatment was required for lacerations, with some time being lost from work. Only 3 of the accidents were reportable under workmen's compensation insurance.

From these figures, it can be concluded that the amount of time lost because of accidents was negligible. The workmen's compensation insurance carrier considered the accident rate in relation to the number of man-hours worked a noteworthy achievement and possibly lower than one would expect in the ordinary manufacturing plant.

Adjustment to the Job

Epileptic employees, of course, have associated emotional disturbances. It has been necessary on occasion to deal with problems arising out of the emotional conflicts of the employee rather than from the presence of dysrhythmic cortex.

The majority of Epi-Hab's employees have performed their duties energetically and economically, often to the envy of the industrial plant subcontracting work to the Epi-Hab plant. However, among the 57 hired during the first year, there were a few with deviate per-

sonality patterns of behavior resulting from a background of disruptive and traumatic experience. These people were just as maladjusted at Epi-Hab as they had been outside in the competitive industrial setting. They performed their work erratically, were unwilling to accept responsibility for adequate performance of a job, and would quit work without any apparent provocation. When they were placed on a job the performance of which fitted well their symbolic needs and defenses, however, there occurred a surprisingly marked improvement in job adjustment. Over a period of time these, as well as the other employees at Epi-Hab, began to show changes in attitude,

changes which brought them closer to integration with co-workers, family, and society.

Summary

An industrial-medical plan, called Epi-Hab L.A. Inc., aimed at the conservation of human energy and restoration of respectability among those afflicted with epilepsy has been put into operation in Los Angeles. Medicine alone cannot counteract the stresses of life that play so important a role in precipitating seizures. Happiness gained through productivity, independence, and social acceptance is as essential to the well-being of the epileptic as it is to those who are not so afflicted.

Rising Income of Blind Vendors

During fiscal year 1956, gross sales at vending stands operated by blind persons rose by 10 percent to a record \$25.8 million. Net annual incomes of the 1,804 blind operators averaged more than \$2,500, an increase of about \$187 over the previous year. In 1956, these operators and their 333 blind assistants earned an aggregate of more than \$5 million, as compared with \$4.5 million earned by 1,721 operators and their employees in 1955.

Under the Randolph-Sheppard Act, as amended in 1954, blind persons licensed through State agencies designated by the Office of Vocational Rehabilitation were authorized to operate vending stands on suitable Federal property and were given priority in setting up such businesses.

The majority of blind operators were trained by the State rehabilitation agencies under the State-Federal program. In addition to drawing up regulations for vending stand programs, the Office of Vocational Rehabilitation assists in educational efforts, surveys potential sites, and works with State agencies in developing, expanding, and improving their programs.